

PATIENT CHOICE and MEANINGFUL DISCLOSURE WORK GROUP PROJECT CHARTER

KEY TERMS

Patient “Opt-Out” Choice: Patient “opt-out” refers to the consent policy adopted by the Illinois Health Information Exchange (ILHIE) Authority for the exchange of patient information through the ILHIE. It allows patient health records maintained by health care providers and institutions participating in the ILHIE to be automatically accessible through the ILHIE unless a patient “opts-out,” that is, exercises his or her choice to deny access to all such information through the exchange.

- If patients do not exercise the right to opt out, their clinical data can be transmitted through the ILHIE. A patient can elect to opt out or revoke the opt-out choice (that is, opt back in) at any time. If a patient opts out of the ILHIE, patient data can be sent by secured email, fax or U.S. Mail.
- Right now, only general medical and mental health information is subject to patient “opt-out”. Specific patient consent must be sought by substance use treatment information, HIV testing and genetic testing, none of which can be sent through the ILHIE until federal and state laws are amended.

Meaningful Disclosure: Meaningful disclosure is the process and the content of the process by which patients and recipients are educated and informed by their providers at the point of care about health information exchange (HIE), how and with whom their PHI will be shared in or through an HIE and their rights to expressly decline any further disclosure of their PHI by an HIE to third parties so as to make a meaningful and informed decision about whether or whether not to participate in an HIE.

WORK GROUP DIRECTIVE

This Work Group will define the scope of patient opt-out consent and identify and recommend a set of appropriate rules, standards and data sharing provisions that the ILHIE and participants to the ILHIE shall adopt and implement to meet the statutory requirement that each patient or recipient whose record is accessible through an HIE shall be provided a reasonable opportunity to expressly decline the further disclosure to third parties of PHI by health information exchange, except to the extent permitted by law, and to revoke a prior decision to opt-out or decision not to opt-out.

This Work Group will define the scope and content of meaningful disclosure for HIE in Illinois, identify and recommend issues and topics that should be addressed by providers at the point of care and develop tools, materials and other resources for use by providers to ensure that patients and recipients receive meaningful disclosure at the point of care about HIEs and their rights with respect to the disclosure of their PHI by an HIE to third parties.

DELIVERABLES

- HIE policies and procedures establishing best practices for patient opt-out consent management;
- Template patient opt-out and revocation forms for use by providers at the point of care; and
- Regulatory language for use in the administrative rule making process around the issue of patient opt-out choice.
- HIE policies and procedures establishing best practices for meaningful disclosure to patients;
- Template language for Notices of Privacy Practices or other deliverables to be given to patients and recipients by providers at the point of care around the issues of opt-out consent and meaningful disclosure such as a potential acknowledgement of receipt of meaningful disclosure, brochures or other written notice of a patient’s or

recipient's right to opt-out of an HIE, which directs the person to an HIE website containing an explanation of the purposes of the HIE and audio, visual and written instructions on how to opt-out of participation.

- Recommendations for HIE website content and audio, visual and written instructions regarding how to opt-out of participation in an HIE.
- Regulatory language for use in the administrative rule making process around the issue of meaningful disclosure to patients.

MAJOR ACTIVITIES

- Teleconferences with and data collections from ILHIE participant entities with respect to their consent models, policies, forms and the content of their disclosures;
- Comprehensive data collection of consent policies, forms and disclosures from other States utilizing an Opt-Out Consent model;
- Comprehensive review of materials and information gathered from ILHIE participant entities and survey of opt-out Statewide HIEs;
- Identification of "best practices" to be incorporated into ILHIE policies, forms and disclosures;
- Drafting, discussion and revision of ILHIE's proposed policies, forms and disclosures.

TIMELINE

- **July/Aug/Sept 2013** – Data Security & Privacy Committee and Regional HIE Work Group meetings and approvals of ILHIE's proposed policies, forms and disclosures
- **Sept 2013** – Status report to the ILHIE Authority Board
- **Nov 2013** – ILHIE's proposed policies, forms and disclosures (Work Group deliverables)

WORKSHOP HANDOUTS

- A template document outlining the policy issues and recommendations underlying the form and content of ILHIE's proposed policies, forms and disclosures;
- Exemplary forms and content from surveys of ILHIE participants and Opt-Out State policies, forms and disclosures;
- ILHIE's proposed policies, forms and disclosures.

STAKEHOLDER ROLE

- Collaborate with ILHIE Authority staff, Work Group members and other stakeholders in carrying out the Work Group's directives and in meeting its major activity objectives.
- Lending each stakeholder's unique perspective, knowledge, training and experience to the task of creating the ILHIE's standards and policies around Patient "Opt-Out" Choice and Meaningful Disclosure.
- Attend Work Group meetings and undertake tasks assigned by the Work Group Co-Chairs until such time as the Work Group's major activity objectives have been achieved.